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# The Experiences of Latino Parents as they Navigate Care for a Child with Autism

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The Experiences of Latino Parents as they Navigate Care for a Child with Autism

By

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MSW Clinical Research Paper

Presented to the Faculty of the

School of Social Work

St. Catherine University and the University of St. Thomas St. Paul, Minnesota

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Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

### **Abstract**

This qualitative study explored the experiences of Latino caregivers as they navigate care for a child with autism spectrum disorder (ASD). Six caregivers participated in a semi-standardized interview containing 14 questions. The data obtained was analyzed using a phenomenological approach to find common themes in the participants' experiences. Findings were organized into two broad themes and sub-themes of positive experiences with service access and delivery and negative experiences with service access and delivery. The sub-themes of positive experiences were as follows: communication, support systems, collaboration, education, and luck. The sub-themes of negative experiences were language access and interpretation, lack of information, limited support and validation from professionals, waitlists and logistics. The findings in this study provide several implications for practice, policy, research and education. Increased access to consistent quality interpretation, increased training for professionals and further evaluation of policies that impact Latino clients are all recommended.

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## **The Experiences of Latino Parents as they Navigate Care for a Child with Autism**

### **Introduction**

The intent of this qualitative research study was to examine the experiences of Latino parents and caregivers of a child with autism spectrum disorder as they navigate systems of care. Autism spectrum disorder (ASD) is a neurodevelopmental disability that can cause challenges in communication, behaviors, and socialization (Centers for Disease Control and Prevention [CDC], 2014). These challenges sometimes result in deficits in social-emotional reciprocity and difficulty developing and sustaining social interactions. Restrictive and repetitive behaviors may create rigidity in thinking and routines which causes distress when a routine changes or transitions (APA, 2013). The CDC recently reported the rates of autism were at one in 88 children in the United States with a higher incidence of ASD reported in boys (CDC, 2014).

ASD has been diagnosed in all cultures, all ethnicities, and across all socioeconomic levels (APA, 2013). Treatment of ASD can happen in a variety of settings, with multiple interventions, and with multiple providers (CDC, 2014). Accessing services and treatments for ASD has been identified as a common barrier for families of children with ASD (Sage & Jegatheesan, 2010). Previous research indicates that cultural barriers between practitioners and clients from culturally diverse populations have made it difficult for caregivers to access medical and mental health services (Welterlin & LaRue, 2007).

Social workers are encouraged by the National Association of Social Workers' (NASW) code of ethics to demonstrate cultural competency and social diversity in

practice (NASW, 2008). It is important for social workers to seek to understand the experience of culturally diverse populations in order to provide ethical treatment and service to their clients. This qualitative research study intends to add information to the current body of research about the experiences of culturally and linguistically diverse populations --- specifically Latino parents --- as they navigate ASD care for their children.

### **Literature Review**

While ASD is generally a well-researched topic, fewer studies have examined how families from culturally and linguistically diverse populations are affected by ASD (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004). Previous studies have identified several important themes which will be addressed in this review, including the prevalence of ASD, cultural factors impacting a family's experience with ASD, barriers to accessing services, and suggested strategies to providing culturally competent interventions.

### **ASD Overview**

Autism Spectrum Disorder (ASD) is described in the DSM-5 as a neurodevelopmental disorder that manifests in individuals as deficits in social communication and restrictive, repetitive patterns of behavior. Social communication deficits may present as a lack of reciprocity in social interactions or as reduced emotional recognition and affect. Individuals might also experience these deficits as a difficulty in

reading nonverbal communication, abnormal eye contact and body language. Many individuals diagnosed with ASD also have difficulty with developing and sustaining relationships with peers (APA, 2013).

Individuals diagnosed with ASD can experience restrictive or repetitive patterns of behavior, interests, or activities. Repetitive motor movements, adherence to routine and highly restrictive interests are some examples of these behaviors. Individuals may also experience hypersensitivity to environmental stimuli, such as sounds, smells, or tactile sensations (APA, 2013).

Deficits in social communication, social interactions, and restrictive behaviors are present in individuals with ASD in early childhood and interfere with daily life. Each diagnostic criterion for ASD is evaluated on a spectrum of severity from level 3, requiring the highest level of support, to level 1, requiring a minimal amount of support. For example, an individual's social communication may be evaluated at a level 2, while his or her restrictive behavior may be evaluated at a level 3 (APA, 2013 pg.52).

### **Prevalence of Autism Spectrum Disorders**

The most recent information from the Centers for Disease Control shows that the rate of children in the United States with an ASD diagnosis has increased from one in 110 in 2006 to one in 88 in 2008 (CDC, 2014). Autism is a developmental disorder that is present at birth, and is found in all cultures, ethnicities, and across all socioeconomic statuses (APA, 2013). However, other research suggests that there is a higher incidence of autism diagnosis among some immigrant populations. Barnevik-Olsson, Gillberg, and Fernell (2010) found that immigration and refugee status was a risk factor for ASD in a

Somali population in Stockholm Sweden (Barnevik-Olsson, Gillberg, & Fernell, 2010).

In Minneapolis, MN, a community report recently released found that Somali children in that city were diagnosed with ASD at a rate of 1 in 32 while Caucasian children were diagnosed at a rate of 1 in 36 (Hewitt et al, 2013). Although these results are not clinically significant for higher rates of autism in Somali populations, these findings do demonstrate that autism is diagnosed at similar rates across many of the ethnicities included in this study.

### **Comorbidity in ASD**

To add to the complexity of the spectrum of an Autism diagnosis, many individuals with ASD also have comorbid mental and physical health disorders. Children with ASD were found to have medical conditions, such as asthma, eczema, and allergies at higher rate than the general population (Kohane, McMurry, Weber, MacFadden, Rappaport, et al., 2012). Individuals with ASD are also more likely to have a seizure disorder (APA, 2013). Sleep, diet, and appetite are also commonly disrupted in a child with ASD, with high rates of children diagnosed with sleep disorders and gastrointestinal dysfunctions. (Kohane, et al., 2012).

About 70% of individuals with ASD also may meet criteria for a comorbid mental health disorder. The more commonly co-occurring mental health disorders in individuals with ASD are attention deficit/hyperactivity disorder (ADHD), anxiety disorders, depression, and disruptive behavior disorder (Levy, Mandell, & Shultz, 2009). Speech and intellectual disabilities are also diagnosed in some individuals with ASD, further adding to the complex picture of ASD (Volkmar & Pauls, 2003).



## **Treatment of ASD**

With the variability of symptoms and comorbid disorders comes a variety of treatment options for individuals with ASD. The highly specialized medical model creates a system where many individuals with ASD receive treatment from more than one professional in more than one area of focus. A study of 552 U.S. parents of children with ASD revealed that, on average, each child was receiving seven different treatment modalities (Green, et al., 2006). Speech therapy, visual strategies, and applied behavior analysis were the leading treatments reported. These results were similar in a study of 60 parents in the country of Jordan, where the average number of services a child participated in was six, with speech, occupational, and physical therapies reported as the most common interventions (AL Jabery, Arabiat, AL Khamra, Betawi, & Abdel Jabbar Sinaria, 2012).

Treatments and interventions for ASD vary greatly depending on the age of the individual and the severity of symptoms. These services can be educational, community-based, medical, and pharmacological. Green et al., compiled a list of 111 possible treatments with which caregivers could respond. Most treatment methods target specific symptoms of ASD. For example, social skill training is a common intervention to teach an individual with ASD social communication and interaction skills. Speech therapy and/or the use of assistive technology are used to target the communication and speech deficits that are often a component of ASD (Levy et al., 2009). While there is no medicine for ASD, many individuals are prescribed pharmacological interventions to target symptoms and co-occurring diagnoses. Medications to alleviate symptoms of

ADHD, depression, and/or anxiety are commonly prescribed to individuals with ASD (Volkmar & Pauls, 2003). Medical interventions including special diets, such as gluten- or casein-free, and sleep aids are commonly accessed by individuals with ASD (AL Jabery et al., 2012).

### **Caregivers Perceptions of ASD Treatment**

With the increased prevalence of ASD diagnosis and the myriad of treatment modalities, researchers have begun to explore the perceptions of caregivers of children with ASD as they navigate this complex system. Parents report a more positive experience of ASD services and providers when they feel like treatment is more collaborative between them and providers (Moodie-Dyer, Joyce, Anderson-Butcher & Hoffman, 2014; AL Jabery et al., 2012). Reports of adequate social support, financial resources, and access to specialized services and providers have also been linked to caregiver reports of positive experiences with ASD treatments (Moodie-Dyer et al., 2014; AL Jabery et al., 2012).

Negative perceptions of caregivers are related to their relationship and access to service providers as well. Delayed diagnoses, communication breakdowns between service providers, lack of financial resources, and long waitlists all contribute to caregivers' negative experiences (Parish, Magana, Rose, Timberlake & Swaine, 2012; Moodie-Dyer et al., 2014; AL Jabery et al., 2012). Caregivers in three different studies of three different culture groups reported experiencing delays in receiving their initial ASD diagnosis. When concerns were brought to professionals, caregivers reported they felt

dismissed, devalued, or blamed for their child's condition (Parish et al., 2012; Moodie-Dyer et al., 2014; AL Jabery et al., 2012).

### **Cultural Factors**

Previous literature has explored how culture can impact a child with ASD.

Cultural beliefs and understandings about disabilities were an indicator of how a family accessed support for their child (Jegatheesan, 2009). Cultural factors, such as religious or spiritual beliefs, were also found to impact a family's acceptance of an ASD diagnosis (Dyche et al., 2004). For example, in a study of three families of Muslim faith, researchers found that they believed that they were given a child with ASD because Allah found them worthy of raising such a child (Jegatheesan, 2011). This was contrasted by a study of Asian American families, who believed that having a child with disabilities was karma or punishment for past wrongdoings (Sage & Jegatheesan, 2010).

The positive or negative view of the origin of a child's autism diagnosis was indicative of how families interacted with the child (Dyches et al., 2004). Families from cultures that hold positive views of the child with ASD tended to include the child in community events, religious services, and family gatherings (Jegatheesan, 2011).

Children who belong to families with negative beliefs about the origin of their disability were not included in larger gatherings or events. Mothers of these children reported living in secrecy and hiding the child's diagnosis from other immediate and extended family members (Jegatheesan, 2009).

## **Barriers**

Much of the research about cultural diversity addresses the many barriers experienced by participants. Common barriers include access to a language or quality interpretation, cultural miscues from providers, and lack of support (Jegatheesan, 2009).

A qualitative study of Asian American mothers of children with ASD found that being unable to communicate in English or have access to quality interpretation was a large barrier to accessing medical services for their child. Even mothers that were competent in English reported that the medical jargon used by professionals was difficult to interpret (Jegatheesan, 2009). Mothers in another study said that providers did not understand how their family communicates. These mothers reported that the therapists made recommendations, such as only speaking English in the home, which was not feasible for their family (Jegatheesan, Fowler, & Miller, 2010). Participants in multiple studies reported discontinuing services because they were frustrated and felt that their providers were acting on cultural stereotypes (Jegatheesan, 2009) (Dyches et al., 2004).

## **Suggested Strategies**

Multiple studies suggest strategies to working cross culturally. By being aware of the challenges and barriers faced by culturally diverse populations, professionals can provide better services (Dyches et al., 2004). Studies also recommend using quality interpretation services, using simple and respectful communication with parents, and being aware of one's own cultural identity (Jegatheesan, 2009). To reduce barriers, studies encourage professionals to use a multi-linguistic approach (increasing access to written and spoken information in clients' preferred language) and to increase

communication among providers (Jegatheesan, 2011). Families report higher satisfaction when they feel empowered to collaborate with their child's service providers (Moodie-Dyer et al., 2014).

In order to provide inclusive care to culturally and linguistically diverse families, professionals should engage families in the diagnostic and treatment process by asking them about their view of the problem and what they think will help (Won, Krajicek & Lee, 2004). Many ASD interventions were developed from a western perspective of individuality, with most of the focus of treatment being on the individual. However, researchers suggest assessing the entire family system in the treatment planning of a child with ASD and allowing for flexibility with implementations of treatment, as culturally and linguistically diverse families may not be well-served with traditional western ASD treatment (Ennis-Cole, Durodoye & Harris, 2013; Won et al., 2004).

## **Conceptual Framework**

### **Cultural Competency and Social Diversity**

This research was developed and conducted through the lens of the concept of cultural competency and social diversity. The National Association of Social Workers (NASW) sets forward a code of ethics for social workers to use as guidelines and standards for practice. Among these guidelines is the ethical standard of cultural competence and social diversity (NASW, 2008).

This ethical standard has three components that outline how social workers can demonstrate cultural competency and social diversity in practice. The first component encourages social workers to understand how culture impacts human behavior and how it functions in the larger society. Social workers are encouraged look for the strengths in each culture group as they relate to the behavior of the individuals and the group.

The second component of cultural competency and social diversity states social workers should educate themselves about their clients' cultures in order to serve them in a manner that is sensitive to their cultural needs and beliefs. The NASW says that social workers should provide services that are sensitive to the differences among their individual clients and the larger cultural groups to which they belong (Code of Ethics, NASW 2008).

Finally, the third component of the cultural competency and social diversity ethical standard asks social workers to develop an understanding of social diversity and oppression at the micro, mezzo, and macro levels of practice (Code of Ethics, NASW 2008).

The concept of culturally competency has drawn some criticism and recommended changes from some current research. Johnson and Munch (2009) present several theoretical objections to the concept and offer the alternative idea of cultural humility. One of the more prominent criticisms of cultural competency is that the word "competency" itself suggests the ability to become competent in cultural knowledge, an act which is neither achievable nor conducive to social work practice. Critics assert that this idea of competence infers that a practitioner could be able to learn everything there is

to know about culture, a feat which is impossible given the fluid nature of culture (Johnson & Munch, 2009).

The idea of cultural humility is suggested as an alternative to culturally competency as the idea of humility suggests a greater level of empathy and learning from the client, rather than attempting to be an expert about a culture and applying that knowledge to a client before fully understanding their world view (Johnson & Munch, 2009). Despite criticism, the NASW continues to reference cultural competency as a core value of social work practice.

The concepts of cultural competency, cultural humility and social diversity provided a framework for this study. The goal of this study was to explore the experiences of Latino parents as they navigate care for their child with ASD and to determine ways in which social workers and other service providers are meeting the needs of this population. This study also explored areas for growth in providing services that are culturally sensitive. This research looked for themes of what has worked well, what has not, and what needs have not been addressed within the context of the experience of Latino parents. In exploring these experiences, this researcher recorded issues of oppression or discrimination as told by the participants at the micro, mezzo, and macro levels. The results of the study were shared with other social workers and professionals in order to increase their understanding of the participants' experiences as it relates to their culture. The resulting information also provides opportunities to advocate for change or to develop services to meet unmet needs.

The researcher has used the concept of cultural competency, cultural humility and social diversity to discuss the implications of the data obtained. Recommendations for social work practice with Latino parents of a child with ASD are also discussed as it relates to this conceptual framework.

## **Methodology**

### **Research Design**

The purpose of this research project is to explore the experiences of Latino parents of a child with ASD as they navigate systems of care. This research is a descriptive study that analyzes qualitative data gathered through the use of a semi-standardized interview with six participants. After the data was obtained, it was analyzed using a phenomenological approach to explore common themes within the participants' life experiences.

Qualitative data was chosen for this descriptive study over quantitative data because it allows for richer descriptions of lived experiences (Padgett, 2008, p. 16). This type of data allows the research to be merged with advocacy for change by bringing the voices of the study's participants to a larger audience (Padgett, 2008, p. 17). Qualitative data was also selected because the goal of this research was to explore the experiences of participants. These experiences cannot be meaningfully or easily expressed by numbers (Berg, 2012, p. 3).

The semi-standardized interview allowed for the flexibility to ask probing follow-up questions, as well as allowed the researcher to provide explanations and clarifications



to questions as needed (Berg, 2012, p. 109). This interview approach was chosen instead of other approaches – surveys or phone interviews, for example – because it also allowed the researcher to gather observational data, such as emotional responses and non-verbal cues (Monette, Sullivan, & DeJong, 2011, p. 186). A face-to-face interview also allowed for more accurate language interpretation, as many of the participants communicated primarily in Spanish (Padgett, 2008, p. 112). A professional interpreter was used in five of the six interviews.

The phenomenological analysis of the data allows the researcher to identify common themes (Padgett, 2008, p. 35) in the parents' recorded life experiences of accessing care and services for a child or children with ASD. This approach to data analysis has been used to enhance social workers' understanding (Padgett, 2008, p. 36) of what it is like to navigate the systems of care through the perspective of a parent of a child with ASD in the Latino community.

## **Participants**

The participants in this study were Latino parents or legal guardians of a child or children diagnosed with Autism Spectrum Disorder (ASD). For the purpose of this research, the participants' child or children had been engaged in specialized care or services for ASD. For example, these services included, but are not limited to, the following: special education services, outpatient behavior therapy, and speech therapy. Therefore, it was important that the selected participants have had interactions with the child's ASD services and providers.

## **Sample**

Participants for this study were selected through a non-probability, convenience sample of current clients of an autism clinic. The researcher provided professionals at the autism clinic with information about the study and an informational flyer for them to distribute to clients that met the criteria for participation (see Appendix C). The flyer was distributed in English and Spanish and stressed that participation in this study was completely voluntary and would not impact participants' current or future relationship with the autism clinic. The flyer provided a brief overview of the study, participation requirements and also asked participants to contact the researcher via phone or email if they were interested in participating. Once a participant contacted the researcher, the researcher reviewed the requirements of participation in the study and again stressed that their participation in this study would be completely voluntary and would not impact their current or future relationship with the autism clinic (See Appendix D). An interpreter was used for this call as needed. The researcher also emphasized that this research was being conducted as a component of the researcher's graduate school program and was not a condition or requirement of their receiving services at the autism clinic. The researcher stressed that their choice to participate or not, would not be disclosed to any employees of the autism clinic. In this call, the researcher answered any questions the respondents had and scheduled a time and place for the interview. The researcher did not provide professionals at the autism clinic with any further information regarding possible participants' decision whether to participate in this study.

The goal of this researcher was to obtain from eight to 12 participants. However, due to time constraints and other barriers, only six respondents participated in this study.

The identity of the participants in this study is only known to the researcher and the professional interpreter.

### **Data Collection**

The primary tool used to collect data in this study was a semi-standardized interview. The participants were interviewed in the participant's home, or in a private place of their choosing. Participants had the option to access interpreters in the interview as needed or as requested. Five of the six participants requested the use of an interpreter for the interview. The researcher scheduled interviews with participants over the phone with the use of an interpreter. The interview consisted of 14 open-ended questions that were developed by the researcher and informed by previous literature. The questions were written by the researcher in clear, concise, non-technical language to provide for easier interpretation. The questions were peer-reviewed and committee reviewed for face validity and reliability. The questions were also reviewed by the interpreter to identify any concepts or words that could be problematic. The interview questions are as follows:

1. When did you first have concerns that something was different about your child?
2. Tell me about your experience with the process of receiving a diagnosis for your child.
3. What was your reaction to receiving the diagnosis?
4. Did the professional providing the diagnosis explain Autism to you in an understandable way? What recommendations did they make?

5. Were you able to get the help you needed after the diagnosis was given?
6. What services has your child received to help with his/ her diagnosis (school, community, medical, county, etc.)?
7. How are you included in the services your child receives?
8. What is your relationship like with your child's service providers?
9. What have service providers done that makes information (progress updates, suggested strategies, evaluation results, etc.) available and understandable?
10. What difficulties have you encountered accessing help for your child?
11. Have service providers ever told you to do something that contradicts your beliefs or your family's needs? (Give an example.)
12. In what ways have service providers been most helpful to you and to your child?
13. How have service providers been sensitive to you and your child's culture or beliefs?
14. How do you think services could be more helpful to your family?

The interview questions focused primarily on the participant's personal experience of having a child with ASD and navigating the various systems involved in that child's care and treatment. Questions about the participants' journey from first

concern for their child to their current diagnosis and treatments in place were asked. Participants were also asked about their experiences and perceptions of their child's services and service providers. The participants were asked about their relationship with service providers and were also asked to identify both positive interactions and areas where services can be improved to meet their child's needs. The interviews were recorded with a password-protected digital audio recorder and the audio files were stored on an access-controlled, encrypted laptop computer. The audio files were securely deleted from the audio recorder once they were transferred to the laptop and were removed permanently from the laptop 30 days after the research had been completed.

### **Data Analysis**

Data was analyzed by using a phenomenological approach because the purpose of this study was to explore the experiences of Latino parents and caregivers as they navigate systems to access services for their child with ASD. Data from the recorded interviews was reviewed, de-identified and transcribed by the researcher. After transcription, the data was reviewed for initial codes and then re-read for manifest and latent content. Dominant themes and implicit themes were identified by the researcher and were used to organize the data collected. The themes and codes identified by the researcher were then tested for reliability by another researcher.

### **Protection of Human Participants**

There were possible risks to participants in this study. These included potential risks to confidentiality and privacy, coercion, and emotional stress. The researcher

worked to minimize these risks by creating a process that from the outset was very clear with participants that their participation was voluntary, and that all information regarding their participation would be kept confidential. The participants were informed that they could choose to end their participation in this study at any time without repercussions (this did not occur and all six participants completed the interview). This was communicated to participants in the flyer given to them, in the follow up phone call with interpreter, and again at the start of the interview.

The researcher ensured that the autism clinic would not know the identity of who choose to participate in the study or not. Participants were informed that their participation – and any identifiable information – was confidential and would not be released to the autism clinic. The researcher stressed the voluntary nature of the study and the confidentiality of it at each interaction with possible participants.

Participation in this study could have been emotionally stressful for respondents. Navigating care and resources for a child with ASD can create stress for the caregivers. To minimize emotional stress, the researcher monitored reactions of participants to ensure that they were not stressed. Prior to beginning the interview, participants were reminded that they may skip any questions they did not want to answer and that they may choose to end the interview and their participation therein at any time. To provide support, the researcher developed a list of local, culturally informed advocacy and support agencies with contact information to provide to the participants at the start of the interview. This list can be found at the bottom of the consent form (see Appendix A).

To address these possible risks, the researcher created a consent form which was reviewed with participants, created a list of advocacy and support resources, and again

reminded participants of the voluntary nature of their participation. The consent form was written by the researcher and was based on a template provided by the University of St. Thomas' Institutional Review Board. The consent form was amended with simple, non-technical language so that it was more easily interpreted into Spanish.

Participants had the option to sign a consent form written in English or in Spanish. The consent form for this study contained information about the purpose of the study, the reason for selecting the individual for participation, the procedures involved in completing the interview and how obtained information would be used. The form also addressed the issues of benefits and risks to participating in the study, issues of confidentiality and the voluntary nature of participation, consent to participate in the study, and the contact information for the researcher and course instructor. The form also addressed confidentiality issues associated with the home environment that the interview would occur in. Family members other than the participants could have been present in the home during the interview at the discretion of the participant. Of the six interviews conducted only the caregivers and their children were present. Prior to the interview, the consent form was reviewed and signed by the participant and the researcher with support from an interpreter as required. Participants were informed that they could withdraw from the study at any time and they may skip any interview questions they did not wish to answer. Participants were given one week post interview to withdraw from the study without their data being used (see Appendix A).

An interpreter confidentiality agreement form was reviewed and signed by the interpreter that was involved in the process. This form also addressed confidentiality and

privacy of the participants and the data obtained. This form was signed by the interpreter and the researcher (see Appendix B).

This research was done with the support of an area autism clinic which could have posed risks to participants as well. This clinic was the site where the initial letter about the study was provided to possible participants by the researcher. In order to avoid coercion of potential participants, all written and oral communication addressed the voluntary nature of the study and that participation would not impact their child's current or future care at the clinic. This was addressed in the letter given to potential participants, the follow up phone call, and the consent form signed before participation (see Appendix C). The employees of the autism clinic were not informed who chose to participate and who did not. Extra care was taken to ensure that participants were informed that the services they receive at the autism clinic are separate and uninfluenced by their participation in the research project.

### **Limitations**

The size of the sample and constraints on time and resources were limitations of this research. The sample size goal of eight to 12 was not reached. The final sample size was six participants. While this provided enough data for analysis, more time and a larger population could have provided even more information and insights into the experiences of Latino parents and guardians navigating a child's diagnosis of ASD. With more time available for the study, a larger number of participants could have been involved, and more financial resources could have been explored and used to cover the cost of additional interpretation of materials. With more time and resources, this researcher could



have expanded the sampling pool to include participants that do not receive services at the autism clinic where this study was conducted. Participants could have been recruited from other medical clinics and schools in the area to provide further perspectives on the subject. Finally, another limitation of the research came from within the structure of the research itself. Working across cultures and languages presents additional challenges and required additional resources external to the researcher, such as quality interpretation and transcription services.

### **Bias**

One bias of this research project was the personal experience of the researcher working with children with ASD and their families. This researcher has past experience working with clients from culturally and linguistically diverse populations and has provided advocacy for these clients in accessing appropriate care and treatment. The researcher's past experience with clients could have biased the questions asked in the interview and could have also impacted the themes and codes analyzed in the data once transcribed.

To confront the possible bias of the researcher, questions were formed with support from previous research on the topic. The questions were reviewed by a group of eight peers to determine that they were written with clear, unbiased, and non-technical language. The questions were also peer-reviewed to determine validity and reliability. Another researcher performed a reliability test of the codes and themes discovered by this researcher to ensure that they were not discovered from a personal bias.

## **Findings**

In analyzing the data gathered, several broad themes emerged. Access to services and service delivery was often discussed by participants in either positive or negative characteristics. Positive characteristics were further broken down into five sub-themes: communication, support systems, collaboration, education, and luck. Characteristics of a negative experience were further broken down into the sub-themes of language access and interpretation, lack of information, limited support and validation from professionals, waitlists and logistics.

### **Characteristics of Positive Experiences**

Several sub-themes were identified in the data gathered from participant interviews. Communication, support systems, collaboration, education, and luck were all common themes discussed by the caregivers in this study. Communication was often discussed in terms of the caregivers' access and ability to communicate with providers. Caregivers often spoke of support systems from family, friends, and trusted professionals as contributing to a positive experience with service access and delivery. Collaboration with family members and among other service providers was another common characteristic of a positive experience. Caregivers also often identified that receiving education about autism and techniques and strategies positively impacted their experience with services and providers. Finally, caregivers also discussed luck as a characteristic of their experience. Many of the participants believed that they have had a positive experience with their services and providers because they "just got lucky."

## **Communication**

Caregivers discussed communication as a characteristic of a positive experience with service access and delivery. Caregivers discussed having consistent and trusted language interpretation as one of the indicative characteristics of a positive experience. For example, one parent said, “I like to work with [name of interpreter] because he helps me explain the things that I need to have explained to the therapist. Because he is consistent and helpful, we have a relationship.” One caregiver reported that she was able to more easily communicate with school providers because there was a Spanish speaking administrative staff on site that she could easily access. Many caregivers also stated that although they understood or spoke English, they still appreciated interpretation for more complex medical and treatment communications.

Caregivers also reported more positive experiences when providers gave them frequent updates on their child’s progress in services. Many caregivers that reported positive communication said they received weekly or bi-weekly updates from providers about their child’s progress. One parent said:

We have very good communication with the school and autism clinic. We meet once a month with the day treatment staff and once a month with the social worker. So we know how he is doing in his programs. We made a plan so that every provider that is working with our child has signed a release so that they can all communicate and be on the same page.

Another caregiver reported that the communication with her service providers contributed to her positive experience. “They always ask us if we have any questions and tell us to call them,” she said. “They let us know techniques and strategies to use. When he wasn’t talking they helped us with all the visuals and everything.”

### **Support Systems**

Many of the participants in this study reported that having a support system of family, friends, and trusted professionals contributed to their positive experience navigating services for their child. Most of the participants reported that these support systems were beneficial in providing recommendations to services and resources as well as emotional support. Most caregivers ended up in services based on the referrals from either trusted professionals or family and friends. Caregivers specifically mentioned relying on their social workers or case managers, pediatricians, and school staff to provide support in accessing services and resources. One family also reported that participating in a support group for parents of children with disabilities provided a form of support and a positive experience.

Our child started getting the services (OT, speech, etc.) at the school and he wasn’t improving at all. After a while they recommended [name of autism clinic] and [name of agency]. Wait, first we went to the autism clinic and our social worker there recommended we go to [name of agency] for a support group for parents of children with disabilities. When we started going to the support group, we realized that we were not the only ones with a child with autism.

## **Collaboration**

Collaboration among providers and with the family was another commonly discussed characteristic of a positive experience with service access and delivery. Caregivers often reported their child was involved in several different services and said that collaboration among providers was contributory to their positive experience. Caregivers also often reported that being included in the treatment process was beneficial to their engagement with services. Many participants mentioned the role of the social worker as a key coordinator and collaborator. Arranging transportation, scheduling outpatient therapy appointments, completing insurance paperwork, communicating to other service providers, and holding onto important paperwork were some of the noted collaboration tasks performed by social workers. Many of the participants reported that due to the language barrier, they relied on their relationship with the pediatrician or social worker to help them get the information for services that they needed. One participant said, “It’s hard to manage all the time to go to all these therapies and go to all these appointments. The doctor had a social worker from the clinic call me with an interpreter to help me with all the appointments.” Another participant said, “I have my social worker keep all my papers. I have too many papers so I give them to the social worker. They are all in English.”

## **Education**

Participants identified that receiving training or education about Autism and strategies to use with their child was contributory to their overall positive experience with services and providers. When participants were asked about what has been most helpful

for them, many of them said it was being taught how to interact with their child. Many caregivers reported that therapists, school teachers, and doctors were most helpful when they could explain autism strategies in clear way and could show them how to implement these strategies. Many parents discussed using a visual system to help facilitate communication which was taught to them by school professionals or by a therapist.

We go to IEP meetings at school and they teach us how to work with his bad behaviors. School taught us how to use pictures to teach him, and also at the autism clinic. When he was going to the autism clinic, someone was coming here once a month to talk about the behavior and now he has been at a special school for kids with autism for 2 years and a therapist is coming here once a week for 2 hours to teach us.

Some caregivers reported receiving education about the diagnosis of autism at the time of their child's evaluation. Several participants reported that prior to their child's diagnosis; their knowledge about autism was limited. Although many of the participants expressed grief about the child's diagnosis, receiving a clear and understandable explanation of autism was considered a positive experience. One participant said, "I couldn't believe it. I thought that kids with autism had higher [more] problems that never went away. But then they explained that there are different types of autism. There are levels and some are higher."

## **Luck**

Many of the participants talked about the importance of "luck" or random chance in regards to their positive experience with autism services and service providers.

Caregivers stated that they “just got lucky” when talking about the therapists and social workers that they work with. Another participant talked about how her child had won a lottery to be selected into a special school for kids with autism. Many of the participants acknowledged that other children and families had not had great experiences with accessing services and therefore view their positive experiences as not common or “lucky.” In a discussion about waitlists, one participant reported, “we didn’t wait at all. I was lucky because I know other families that want to go to the autism clinic but the waiting list is very, very long.”

### **Characteristics of Negative Experience**

Many participants also shared information and stories about autism services and service delivery that contributed to a negative experience. Many of the negative experiences discussed by participants were also barriers to accessing services as well. This theme was further broken down into five sub-themes of characteristics of negative experience to further analyze participants’ shared experiences. The following sub-themes were identified: language access and interpretation, lack of information, limited support and validation from professionals, waitlist and logistics.

#### **Language Access and Interpretation**

Language access and interpretation was the most frequently discussed characteristic of a negative experience. Several common experiences were described by caregivers in this theme. Inadequate interpretation, inconsistent or lack of interpreter use,

and professionals who are unfamiliar with how to work with interpreters were often reported by participants. Furthermore, many participants reported that they do not have a way to express concerns when they arise due to language barriers. Caregivers described feeling “stuck” because the interpreter is the person they need to communicate with the professionals. If the interpreter is not doing their job properly, there is then no way for the caregivers to express this.

Many of the participants reported negative experiences with inadequate interpreters. One participant said:

One day at the autism clinic they had another interpreter and the interpreter said, “Hello, my name is *whatever*, I’m going to be your interpreter and every time you want to talk, you have to raise your hand.” And I said, “Why? Other interpreters don’t work like that.” And the interpreter was like, “Yeah, this is how I work.”

Some caregivers reported that they are able to understand some English and therefore could understand when an interpreter was or was not interpreting correctly. One participant reported that she has had to ask an interpreter to interpret what she was saying because he was just sitting quietly in the session. Some of the caregivers reported having to end or cancel sessions due to poor interpretation.

Inconsistent or no use of an interpreter was also frequently discussed as a characteristic of negative experience with services. Some caregivers reported that interpreters are used infrequently during sessions and sometimes not at all. One



participant reported having to rely on her older daughter to interpret her younger child's therapy session for her.

Before school and the autism clinic, I was lost because I was bringing my child to an outpatient therapy clinic and they would not use an interpreter. So I would drop off my kid and they would take him back and there wasn't any communication. The therapist would occasionally try and talk to me, but I didn't understand her because she would only speak English. When I had any worries, I used to bring in my daughter to ask for help.

Some caregivers also reported that, although they go to weekly appointments for their child, an interpreter may only be present once a month. Caregivers reported confusion over why interpreters were used or not. One caregiver shared that she no longer attends the weekly appointments with her child for this reason:

I used to go in the beginning but there wasn't an interpreter there for the clinicians to talk to me so she started bringing my other child to help. So there was an interpreter a couple times, but the clinician told the interpreter that they didn't need them anymore and they started giving the child a piece of paper for him to bring home that had information about what they are working on. They send home a note everyday with what he has been working on in session now, but it is in English.

Some of the caregivers also reported that the manner in which professionals engaged with the interpreter also impacts their experience with services and professionals. One parent reported that she has had professionals that will only talk to and look at the interpreter. “It’s like they forget I am still in the room!” she exclaimed. Another participant shared that when professionals use too many clinical terms or jargon without explaining the meaning, the interpreter is unable to fully express the intention of the professional and often leaves important information out.

### **Lack of Information**

Several respondents in this study attributed lack of information about services, resources, and autism in general as a characteristic of a negative experience. When discussing the multitude of autism services available to children, one parent reported, “It has been confusing and frustrating because I didn’t know about one autism clinic and I have some doubt about which one [autism service] would have been better for my son.” Another participant reported that he did not get a lot of information about autism at the time of his child’s evaluation. He used the internet to find more, which he reported was even more unhelpful based on the amount of information and misinformation available.

The lack of information was often discussed by participants when they were asked about their thoughts on improving service delivery. Many participants reported that they did not know enough about the current services to offer an opinion about how they could be more helpful. Some caregivers stated that more information about what resources are available in a language they understand would be an improvement. One participant said,

“The way to improve the most is for me to understand what is going on. To understand, I need to have information in my language. And that is where I don’t always have access.”

### **Professional Support and Validation**

Service access and delivery was reported by caregivers to be negatively affected by the lack of support and communication received from the professionals the family was working with. Several participants reported that their initial concerns for their child were not taken seriously by the professionals they were seeing. This led to some delay in diagnosis and access to services.

Since he was three months old the school district would come into the home. And we would tell the teachers that something was wrong and something is different and the teachers told us that it was too young to diagnose. At the same time, we were going to the pediatrician and telling him the same thing, and the pediatrician said the same thing that he was too young to diagnose.

Another participant reported that her first experience receiving a diagnosis occurred in the waiting room of a neurology clinic was negative. “I went to the neurology and they, you know, take forever to come out and my child was sitting over there (in the lobby) and she [the neurologist] come out and looks at him and said, ‘Oh he is autism.’ She hasn’t even talked to him, but she said, ‘He is autism.’”

## **Waitlist and Logistics**

Caregivers frequently identified waitlists and the logistics of accessing services as a barrier and a characteristic of a negative service access experience. Some participants reported that they have been on waitlists for a specialist for over a year and have not yet heard if the child will be accepted into the service. Other logistical difficulties that participants noted included transportation to appointments, scheduling and managing several appointments a week, and childcare for other children in the family. One participant said that although she was grateful for the progress her son has made, she still felt overwhelmed by the difficulty she encountered navigating so many different services. “I have been going 3-4 times a week for different appointments. I was overwhelmed and wanted to quit the services but now when you see the progress my son makes in the programs, it’s worth it,” she said.

Participants in this study also discussed how the process of navigating all the services impacts their family. Childcare for other children is not always available. While having to attend so many appointments a week has made it difficult for some caregivers to find and keep employment.

Dad is working so it is pretty much me that has to go to everything and take care of it all. It is not easy. It’s been a very difficult process. The dad has been trying to go to at least the most important appointments and we try to spend more time with the kids.

## Discussion

This study aimed to explore the experiences of Latino caregivers as they navigate care for a child with autism. The data gathered in this study was analyzed and categorized into two broad themes and then further analyzed into sub-themes. Broad themes that were found were (1) characteristics of a positive experience with service access and delivery and (2) characteristics of a negative experience with service access and delivery.

The caregiver participants in this study reported numerous characteristics of a positive experience with service delivery and access. The five sub-themes that were discovered were communication, support systems, collaboration, education, and luck. Caregivers in this study reported that quality interpretation and consistent communication and collaboration with service providers were characteristic of a positive experience. This finding is similar to previous research on the topic done by Moodie-Dyer, et al. (2014), who found that families reported higher satisfaction with services when they had more collaborative and communicative relationships with service providers. Support systems, both formal and informal, were identified in this study to be characteristics of a positive experience navigating services. This echoes previous research that found support systems played a role in a parents experience with parenting and accessing for a child with autism. Multiple studies have also found themes in reported collaboration, education, and being “lucky” as attributes to positive experiences with autism service access and delivery (Moodie-Dyer et al., 2014) which was also a theme discussed by the participants in this study.

The theme and related sub-themes of characteristics of positive experiences with service access and delivery that were reported by participants in this study were similar to findings in the existing research. Although there is a lack of literature about Latino caregivers' experience navigating care for a child with autism, there is some research about caregivers from the general population's experience with autism service and delivery.

The participants in this study also described several characteristics of negative experiences with service access and delivery. The sub-themes of negative experiences with service access and delivery that were identified by participants were as follows: barriers to language access and interpretation, lack of information, limited support and validation from professionals, and waitlists and logistics. Several of the themes reported by participants in this study are also found in existing literature. Delay in receiving diagnosis and reported feelings of not being heard by practitioners was a contribution to barriers and negatives experiences for other caregivers (Parish et al., 2012; Moodie-Dyer et al., 2014; AL Jabery et al., 2012), which was similar to reported experiences of participants in this study.

Much of the existing literature about cultural barriers to services includes discussion on language access and interpretation, similar to the findings of this study. Inability to access quality interpretation was a main barrier to accessing and staying engaged in services for participants in a study of Asian American caregivers (Jegatheesan, 2009). This was also congruent with the findings of this study. Waitlists and the logistics of navigating several services for a child with autism were also found to

be characteristics of a negative experience with service access and delivery in this study, which mirrors existing research about the contribution of waitlists and communication breakdowns' impact on experiences with service access and delivery (Parish et al., 2012; Moodie-Dyer et al., 2014; AL Jabery et al., 2012).

Some research on caregivers' experiences navigating care for a child with autism found that caregivers' experience was impacted by financial resources. Although, many of the participants in this study may likely have financial concerns affecting their child's care, this was not reported by participants as a factor in service access and delivery.

### **Implications**

The findings for this study provide several insights into how Latino caregivers have experienced navigating care for a child with autism. Using the themes of characteristics of positive and negative experiences with service access and delivery, several implications can be made in future practice, policy, research, and education.

#### **Practice**

Several implications for practice can be drawn from the findings in this study. Participants reported limited language access, both in printed materials and verbal communication, which contributed to a negative experience. It is recommended that interpreters should be used with consistency at all encounters with family members and providers. Many of the participants reported situations when interpretation was not used at all when they attended an appointment. This created barriers for the family to ask

questions and receive feedback and learn strategies worked on in that treatment session. Agencies and providers should then strive to eliminate those barriers by using consistent interpretation with families at each interaction. Furthermore, caregivers identified that working with a familiar, skilled interpreter increased their engagement and comfort level in communication. Based on these findings, providers and agencies should strive to provide training to interpreters and hold them to the level of professionalism of other clinical staff. Many companies use a third party to contract for their interpreter services. These interpreters may be different every session and do not necessarily receive training in interpreting for autism services. Having a new interpreter each week makes it difficult for families to build relationships and trust in the information the interpreter is interpreting. This system has created barriers for families who have been unsatisfied with the interpretation, as they are not given a way to give feedback about the interpretation services. Many worry about retribution if they did raise concerns. Providers and agencies should consider this in serving clients from culturally and linguistically diverse populations. By hiring in-house cultural and language interpreters, agencies would be able to provide increased language access to families for all areas of service, from scheduling to treatment. Agencies and providers should also routinely assess satisfaction with interpreters and provide a way for clients to report difficulties they encounter.

Increasing language access should also include increasing caregivers' access to printed communications in the language they prefer. Participants reported receiving many different notes and treatment plans, all of which were in English. For a caregiver who cannot read English, these papers do not provide any meaning. Many participants reported that they then give them to their case manager. Providers and agencies should



explore the benefit of providing some written communication or documentation in the caregiver's preferred language. Participants also discussed increased information about resources and autism in general would be helpful to have in their preferred language. Providers and agencies should also continue to develop written materials and flyers about resources and events into languages preferred by caregivers.

Many of the participants in this study, as well as in previous literature, stated that being taught and shown how to implement the strategies that schools and providers use is extremely helpful and valuable. As discussed in previous literature, many autism services focus mainly on the individual with the diagnosis (Ennis-Cole, Durodoye & Harris, 2013). Therefore providers and agencies should consider the whole family system and increase educational opportunities for caregivers when planning a child's treatment interventions. Based on the findings in this research and existing literature, any educational information provided to caregivers, should be given to them in a language they understand and with a lens of culturally humility.

Finally, this study's findings on the importance of collaboration and coordination indicate the importance of social work and case management. Participants in this study reported stress as they navigated the multiple services in which their child participates. Many of the caregivers also reported that having a professional help them navigate services was a positive and beneficial experience. Based on these findings and the findings in previous literature, case management and or a social worker involvement should be highly utilized. With the number of barriers experienced with language access and cultural differences, having a supportive professional to educate, advocate, and

connect with resources would be highly beneficial to all caregivers navigating care for a child with autism.

## **Policy**

The findings in this research have implications for policy on both the mezzo and macro level. This research specifically looked at caregivers' experience with autism service and delivery. Many of the policy implications focus on an agency or mezzo level. Policies within an agency provide professional guidance to providers' practice with clients. Agencies should work to create policies that encourage practice standards that include the recommendations discussed above. For example, agencies should explore how their current policies may be contributing to barriers that caregivers have reported and then work to implement new policies that increase quality language access and consistent interpretation. Agencies should also explore their current models of service delivery to create more opportunities for professionals to provide to parents education and training that caregivers have reported is so beneficial.

Caregivers in this study and in previous literature have discussed logistics such as schedules, multiple appointments, and waitlists as contributing factors to negative experiences. Agencies should explore their existing systems and policies to determine how they contribute to these barriers.

On a macro level, the findings of this research would suggest further evaluation in state and federal funding for services and to explore how those policies impact this population. Caregivers in this study were impacted negatively by insurance issues, medical transportation, and waitlists. Some of these programs have been created and are

funded through state health care funding and county budgets. Policies in these program areas at the state and county level should be evaluated to explore if there are ways in which current policies have bias or unintended negative consequences for Latino caregivers. Social workers should also explore how policies impact waitlists and how some families are able to get into services quickly, while others must wait.

## **Research**

These findings would suggest that more research on this subject would be extremely valuable. In exploring previous literature on the topic, there is not an abundance of studies that specifically study the experience of Latino caregivers. A larger sample of participants would provide even more rich data to be explored. Future research on the topic should be explored with other diverse populations to explore further any themes in similar experiences.

Many of the themes and sub-themes in the findings would be recommended for further study. Perhaps a survey could be developed to further explore the impact of language access on the perceived quality of services. A comparative study of the amount of quality interaction with service providers and Latino caregivers and English-speaking families could reveal possible biases or discrimination in service delivery. Autism services and programs and providers are constantly changing. Future research on the topic is recommended to explore how professionals have implemented strategies of cultural humility into practice and how that impacts caregivers' perceptions of service delivery.

## **Education**

The findings of this research study indicate implications for increasing education for providers about working with interpreters. Many of the caregivers reported that some professionals would forget to address them and only talk to the interpreter, would too often use jargon, or not explain the concepts. Further education on how to most effectively work across language and culture barriers would be impactful in communication and service delivery to caregivers and their child.

Similarly, continued education on working cross culturally and training on cultural humility are recommended to providers and agencies to work to increase information and empathy for the populations served. While many agencies and educational settings include this training, it is recommended that more education include the voices of diverse populations to further foster empathy for the lived in experience and encourage more understanding of the barriers in order to provide more proactive service.

## **Conclusion**

Autism spectrum disorder is a complex neurodevelopmental disorder that impacts individuals and their caregivers in a variety of ways. The rate of individuals diagnosed with autism has increased over the past decade and is now estimated to be one in 88 (CDC, 2014). Autism is diagnosed in all cultures, socioeconomic statuses, and ethnicities. Researchers have begun to explore how autism is understood and navigated across some cultures; however, there is limited research about the specific experience of Latino

caregivers. Existing literature suggests that language and cultural barriers between caregivers and providers of autism services can impact service access and delivery.

This study aimed to explore the experiences of Latino caregivers of a child with autism as they navigate services and care for the child. This study explored what has worked for families, what has not worked, and what recommendations they had for improvements. Six interviews were conducted with caregivers, three of which included both mother and father. The interviews were analyzed for themes and sub-themes and two broad main themes were found with several sub-themes. The two broad themes were (1) characteristics of a positive experience with access and service delivery and (2) characteristics of a negative experience with service access and delivery. The first theme was further broken down into five sub-themes of communication, support systems, collaboration, education, and luck. The second theme of characteristics of a negative experience with service access and delivery was further analyzed into four sub-themes of language access and interpretation, lack of information, limited support and validation from professionals, waitlist and logistics. Much of the existing research about caregivers' experiences was conducted with variety of different populations as the target participant. Despite the difference in populations, this study found many similarities in findings as those from previous research.

Implications based on the finding were recommended for practice, policy, research, and education. Specific practice recommendations were made to providers to increase the language access for caregivers by including quality interpreters with increased consistency and by increasing access to printed materials and documentation in

the preferred language. Additional suggestions to increase opportunities to provide education and demonstration of therapeutic strategies and to also increase the utilization of social work and case management to support collaboration and coordination were also made. Other implications for evaluating policies to explore ways to encourage practice changes were suggested along with recommendations for future research and professional education.

The NASW states

Social workers should promote policies and practices that demonstrate respect for difference, support the expansion of cultural knowledge and resources, advocate for programs and institutions that demonstrate cultural competence, and promote policies that safeguard the rights of and confirm equity and social justice for all people.

Based on the findings of this research and the NASW code of ethics, social workers should continue to evaluate their own practice or the practice of their agencies to explore areas for continued advocacy for increased language access and culturally humility. Providers should attempt to learn from their clients to try to understand their view of the problem and what would be most helpful for them. Quality interpretation should be used consistently and social workers should receive training in working with interpreters if they are uncomfortable or unfamiliar. When working with an interpreter, social workers should ensure that they are communicating clearly, respectfully and without jargon.

This research intended to explore the experiences of Latino caregivers of a child with autism with the goal to bring their perspectives of what has and has not worked in navigating care to a larger audience. The data gathered provided feedback about how caregivers have navigated care and how things could be improved.

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**Appendix A- Consent Form****CONSENT FORM  
UNIVERSITY OF ST. THOMAS****The Experiences of Latino Parents as they Navigate Care for a Child  
with Autism**

IRB # 699857-1

I am conducting a study about the experiences Latino parents have as they navigate care for a child with Autism. I invite you to participate in this research. You were selected as a possible participant because of your experience accessing services and care for your child with Autism. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Emily Tibbetts, a graduate student at the School of Social Work, St. Catherine University /University of St. Thomas and supervised by Dr. Kendra Garrett Ph.D.

**Background Information:**

The purpose of this study is to gather further information about how Latino parents and caregivers access care for a child with Autism and their perceptions on the care and services they have received. Information gained in this study may be used to adjust and improve service delivery for Latino children with ASD.

**Procedures:**

If you agree to be in this study, I will ask you to do the following things: Participate in one 60 minute interview consisting of 14 questions on the topic. An interpreter will be available for the interview as needed. The interview will be audio taped and transcribed by me, Emily Tibbetts. All identifiable information will be kept out of the transcription. The transcribed data will be reviewed by a fellow student for a reliability check and will be compiled into a final report that will be published by St. Thomas University.

**Risks and Benefits of Being in the Study:**

The study has some risks to privacy and confidentiality. In order to protect your privacy and confidentiality, all identifiable information will be removed from any data obtained. To further protect your privacy, the agency, [agency name] and its employees will not be informed of your decision to participate or not participate. The interview will focus on your personal experience navigating systems of care for your child with ASD which may cause feelings of distress. Contact information for area advocacy agencies are listed below should you feel the need for support. You may skip any questions you do not want to answer and you may withdraw from this study any time before or during the interview. If you chose to withdraw after the interview is completed, you may inform me within one week post interview and your data will not be used.



The study has no direct benefits.

**Confidentiality:**

The records of this study will be kept confidential. All personal identifiable information, such as names, dates, or names of agencies receiving services from, will be removed from the transcription. Research records will be kept on a password protected encrypted laptop. A research partner and my research professor will see a full transcript of the interview, but will not know who you are. The agencies you receive services from, such as [agency name], will not be informed of your participation in this study nor will they receive information obtained in the interview. Findings from the transcript will be included in a final report that will be published by the university. The audiotape and transcript will be destroyed by May 20th, 2015. This consent form will be kept in a locked file cabinet in a locked office room for 3 years as per federal guidelines. This researcher is a mandated reporter according to Minnesota state law (MN Statute, 2005, 626.556); which requires me to make a report either verbal or written, if I know of or have reason to believe a child is being neglected or abused, or has been neglected or abused within the past 3 years.

**Voluntary Nature of the Study:**

Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the interview at any time. Your decision whether or not to participate will not affect your current or future relations with [agency name] and [agency name] will not be informed of your decision. Your decision whether to participate or not will also not affect your current or future relationship with St. Catherine University, the University of St. Thomas, the School of Social Work, or [agency name]. If you decide to participate, you may withdraw up to one week after your interview by contacting the researcher directly at the phone number listed below. Should you decide to withdraw, data collected about you will not be used.

**Contacts and Questions**

My name is Emily Tibbetts. You may ask any questions you have now. If you have questions later, you may contact me at [phone number] or [phone number] or you can contact Kendra Garrett at [phone number]. You may also contact the University of St. Thomas Institutional Review Board at 651-962-6038 with any questions or concerns.

**You will be given a copy of this form to keep for your records.**

**Statement of Consent:**

I have read the above information. My questions have been answered to my satisfaction. I am at least 18 years of age. I consent to participate in the study and to be audiotaped.

☐

Yes. I consent to be audiotaped.

☐

No. I do not consent to be audiotaped.

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**Signature of Study Participant**

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**Date**

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**Print Name of Study Participant**

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**Signature of Researcher**

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**Date**

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**Advocacy Agencies**

Pacer Center – MN  
952- 838-9000

The ARC – Greater Twin Cities  
952-920-0855

DAC Family Center – St. Paul  
651-293-1748

**Appendix B –Consent Form Spanish Version****FORMATO DE PERMISO  
UNIVERSITY OF ST. THOMAS****La Experiencia de Padres Latinos Navegando el Cuidado para un Niño  
con Autismo**

IRB # 699857-1

Estoy conduciendo un estudio acerca de las experiencias de padres Latinos navegando el cuidado para un niño con autismo. Lo invito a participar en esta investigación. Usted fue seleccionado como posible participante por sus experiencias obteniendo servicios y cuidado para su niño con Autismo. Por favor lea este formato y haga las preguntas que tenga antes de estar de acuerdo de participar en el estudio.

Este estudio es conducido por Emily Tibbetts, estudiante graduado de la Escuela de Trabajo Social del St. Catherine University /University of St. Thomas y supervisado por Dr. Kendra Garrett Ph. D.

**Antecedentes:**

El propósito de este estudio es reunir más información acerca de cómo los padres latinos y los cuidadores obtienen cuidado para un niño con Autismo y sus percepciones del cuidado y los servicios que han recibido. La información obtenida en este estudio puede ser utilizada para ajustar y mejorar el servicio dado para los niños Latinos con ASD.

**Procedimientos:**

Si usted está de acuerdo de participar en este estudio, le pediré las siguientes cosas: Participar en una entrevista de 60 minutos, consistiendo en 14 preguntas del tema. Un intérprete estará disponible para la entrevista si se necesita. La entrevista se audio grabará y transcribirá por mí, Emily Tibbetts. Toda la información de identificación no se incluirá en la transcripción. Los datos transcritos serán revisados por un compañero estudiante para checar por confiabilidad y serán completados en el reporte final que será publicado por la Universidad de St. Thomas.

**Riesgos y Beneficios de Participar en el Estudio:**

El estudio tiene algunos riesgos de privacidad y confidencialidad. Para proteger su privacidad y confidencialidad, toda la información identificable será removida de cualquier dato obtenido. Para proteger más su privacidad, la agencia, [agency name] y sus empleados no serán informados de su decisión de participar o no participar. La entrevista se enfocará en su experiencia personal navegando el sistema de cuidado para su niño con ASD lo cual puede causar sentimientos de estrés. Información de contacto para agencias de defensoría en el área están enlistadas abajo en caso de que sienta que necesite apoyo. Usted puede saltarse las preguntas que no quiera contestar y puede retirarse de este estudio en cualquier momento antes o durante la entrevista. Si usted quiere retirarse después de que la entrevista es completada, debe de informarme en una semana de la entrevista y sus datos no serán utilizados.

El estudio no tiene beneficios directos.

**Confidencialidad:**

Los records de este estudio serán mantenidos confidencialmente. Toda la información personal identificable, como nombres, fechas o nombres de las agencias de las cuales recibe servicio, serán removidos de la transcripción. Los records de la investigación serán mantenidos con un password protegido en una laptop. Un compañero de investigación y mi profesor de investigación verán la transcripción completa de la entrevista, pero no sabrán quién es usted. Las agencias de las que usted recibe servicios, como [agency name], no serán informadas de su participación en este estudio ni van a recibir cualquier información obtenida en la entrevista. Lo que se encuentre de la transcripción será incluida en el reporte final que será publicado por la universidad. El audio y transcripción serán destruidos para Mayo 20 del 2015. Este formato de permiso se mantendrá en un archivero bajo llave en una habitación de oficina con llave por 3 años según las pautas federales. Este investigador es un mandato de reportar de acuerdo con la ley del estado de Minnesota (MN Estatuto de 2005, 626.556); lo cual me obliga a hacer un informe verbal o escrito, si sé de o tiene razones para creer que un niño está siendo maltratado o abusado, o se ha descuidado o maltratado en los últimos 3 años.

**La Naturaleza Voluntaria del Estudio:**

Su participación en este estudio es enteramente voluntario. Usted puede saltarse cualquier pregunta que no quiera contestar y puede parar la entrevista a cualquier momento. Su decisión de participar o no, no afectará sus relaciones futuras con [agency name] y [agency name] no será informado de su decisión. Su decisión de participar o no, no afectará su relación actual o futura con la Universidad de St. Catherine, Universidad de St. Thomas, la Escuela de Trabajo Social o [agency name]. Si usted decide participar, usted puede retirar hasta una semana después de su entrevista poniéndose en contacto con el investigador directamente al número de teléfono que aparece debajo. Si usted decide retirarse, los datos recabados acerca de usted no serán utilizados.

**Contactos y Preguntas**

Mi nombre es Emily Tibbetts. Usted puede hacerme cualquier pregunta que tenga. Si tiene preguntas después, me puede contactar al [phone number] o [phone number] o puede contactar a Kendra Garrett al [phone number]. Usted puede también contactar a la Junta de Revisión Institucional de la Universidad de St. Thomas al 651-962-6038 con cualquier pregunta o preocupación.

**Se le dará una copia de éste formato para que lo guarde en su archivo.**

**Declaración de Consentimiento:**

He leído la información anterior. Mis preguntas han sido contestadas a mi satisfacción. Tengo por lo menos 18 años de edad. Doy permiso de participar en el estudio y de ser audio grabado.

☐ Sí. Yo doy permiso para ser grabada en audio.

☐ No. Yo no doy permiso para estar grabada en audio.

\_\_\_\_\_  
**Firma del Participante del Estudio**

\_\_\_\_\_  
**Fecha**

\_\_\_\_\_  
**Nombre del Participante del Estudio**

\_\_\_\_\_  
**Firma del Investigador**

\_\_\_\_\_  
**Fecha**

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**Agencias de Defensoría**

Pacer Center – MN  
952- 838-9000

The ARC – Greater Twin Cities  
952-920-0855

DAC Family Center – St. Paul  
651-293-1748

**Appendix C –Interpreter Confidentiality Agreement**

Project: The Experiences of Latino Parents as they Navigate Care for a Child with Autism

I, \_\_\_\_\_ agree to provide professional interpretation for this study. I agree that I will:

1. Keep all research information that is shared with me confidential by not discussing or sharing the information in any form or format (e.g. disks, tapes, transcripts) with anyone other than the researcher who is the primary investigator of this study.
2. Keep all research information in any form or format (e.g. disks, tapes, transcripts) secure while in my possession, including emails or hand written notes.
3. Erase or destroy all research information in any form or format that is not returnable to the primary investigator (e.g. information stored on a computer) upon my completion of the research interpreter task.

By signing below, I am stating that I understand what is being asked of me and I agree to the confidentiality terms listed above.

Signature\_\_\_\_\_

Date\_\_\_\_\_

### **Appendix D – Study Information Flyer English**

Hello! My name is Emily Tibbetts. I am a social work graduate student at the University of St. Thomas and a clinician at [name of agency]. As part of my work as a graduate student, I am doing a project to find out more about the experiences Latino parents have accessing services and care for their child with Autism. If you choose to participate you will be asked to participate in one 60 minute interview with me. A professional interpreter will be provided if you like. I will ask 14 questions about your experience navigating your child's care and things that have been helpful and things you would like to be better.

The goal of this project is to help professionals better understand Latino parents' perspective and identify ways professionals can provide Autism services in a culturally sensitive manner. This study also hopes to examine unmet service needs for children with ASD and their families.

Your participation is completely voluntary and will not affect your current or future relationship with [name of agency] or your current or future relationship with the University of St. Thomas. If you chose to participate, you and your child's identity will be kept private and [name of agency] will not be informed. [name of agency] will not know if you chose not to participate.

If you are interested in participating in this project or have any questions about the project, please contact me. My private phone line is [phone number] and my email is [\[email address\]](#). I will have an interpreter available as needed. Thank you for your time!

### **Appendix E- Study Information Flyer Spanish**

¡Hola! Me llamo Emily Tibbetts. Soy una estudiante del programa postgrado de trabajo social en la Universidad de St. Thomas y una profesional en [name of agency]. Como parte de mi trabajo de estudios postgrados, hago un proyecto de investigar las experiencias que tienen los padres latinos mientras obtienen servicios y cuidado para su niño con autismo. Si usted decida participar, participare en una entrevista de 60 minutos conmigo. Un intérprete profesional será provisto si usted lo quiera. Le preguntaré algunas preguntas sobre tu experiencia de manejar el cuidado de su niño, las cosas que han sido ayudante y cosas que a usted le gusta que mejoren.

La meta de este proyecto es ayudar a los profesionales entender en una manera mejor la perspectiva de los padres latinos, e identificar maneras en las cuales los profesionales pueden proveer servicios de autismo en una manera sensible al respeto a la cultura. Este estudio también quiere examinar necesidades de servicio no cumplidas para niños con autismo y sus familias.

La participación de usted es completamente voluntaria y no afectará su relación actual ni futura con [name of agency] o su relación actual o futura con la Universidad de St. Thomas. Si usted decida participar, las identidades de usted y su hijo/a quedaren privadas y [name of agency] no fuere informado. También [name of agency] no supiere si usted decida no participar.

Si usted está interesado en participar en este proyecto o tiene alguna pregunta sobre el proyecto, por favor llámeme. Mi línea telefónica privada es [phone number] y mi correo electrónico es [email address]. Yo puedo hablar un poco de español y puedo tener un intérprete disponible cuando sea necesario. ¡Gracias por su tiempo!



## **Appendix F – Phone Script**

Hello! Thank you so much for your possible willingness to participate in my project for my master of social work program. I am hoping to interview 8-12 Latino caregivers of children with autism about their experience navigating services for their child. The interview consists of 14 questions about your experience navigating autism services with your child and should last about an hour. This interview will also be audiotaped.

Your participation is completely voluntary and will not affect your current or future relationship with Fraser or the University of St. Thomas. If you chose to participate, you and your child's identity will be kept private and [name of agency] will not be informed. [name of agency] will not know if you chose not to participate. Participation in this study does contain some risk to your privacy and confidentiality. There is also some emotional risk as discussing your experiences may trigger feelings of distress.

Are you interested in participating in this project?

**Answer “yes” response:** Thank you for your interest. At this time the next step is to schedule a time and place for us to meet. I can come to your home or we can find another confidential place, like a library. I hope to do these interviews in February. On the day of our scheduled interview, we will first review the participant consent form and discuss any further questions you may have and to review the process of participating in this study. Once we have reviewed and signed the consent forms, I will start the audiotape and will begin the 14 question interview. I will have a professional interpreter we if needed. The

interpreter and I will both sign a confidentiality agreement and keep your identity confidential. Thoughts and experiences you share in the interview will be used in my final paper, but any information about you or your child's identity will be kept private and confidential.

Do you have any questions for me at this time?

Just so I have a head count of possible interviewees, I'm wondering if you would still be interested in participating in my project?

Great! When would you be available to meet for this interview?

Thanks a bunch! Please call me with any questions or if you need to cancel or reschedule at

[phone number].

**Answer “no” response:** Thank you so much for your time. I understand you are not interested in participating in this study and I will not be contacting you any further. You may call me at [phone number] if you have any future questions or concerns.